

Summary of ECD Global Alliance Internet Chat

18 Mar 2017

8 Attendees

- A new chatter came on and told his story. He was diagnosed with ECD in February 2015. He had lost over 105 lbs in weight and was always tired. After different tests and biopsies, he was found to be BRAF positive. He was treated with 150 mg twice daily of dabrafenib (D). After several months, this was reduced to 100 mg 2x daily, and after an MRI, lowered to 50 mg 2x daily. After another MRI at one year he was taken off D.
He has had no side effects from D, but he has balance issues. He uses a wheelchair, but can use a walker for short distances. He would urge anyone with ECD to talk to their doctor about being on D. It was pointed out that usually remission is defined by PET, not MRI.
- A member, who has had treatment with vemurafenib (V), said that he was "amazed" by this use of D, and that he was now off treatment. He is aware that it is a "big risk" to come off V or D. Some people have had flareups after 3 months.
- Another member said that he was also on D at full dose, 600 mg per day. He hopes to decrease in June after his next PET. Vemurafenib used to give him a rash, and D doesn't. He has some pain in the left arm and shoulder. His last PET/MRI showed improvement, but he has restricted movement – it is hard to get a coat on! He thinks that this is getting better. He wants to get "back in the gym", as he is getting fat! It was said that if he starts some physical therapy along with taking D, he should regain movement.
- The member on V is taking 2 pills a day (a full dose is 8). He is thinking of switching to D as well, but "can't find a reason to". He has no symptoms, just sun sensitivity from V, and mild double vision on far left, which was due to an eye surgery.
He was diagnosed in April 2014, and has been on V since May 2014. He said that, for many years, he couldn't move his arms or lift them up all the way. His son, who was a catcher, used to ask him to pitch to him. He would throw a dozen pitches, and his shoulders would hurt really bad, but this doesn't happen anymore. He can even lift weights! The shoulder problems were all due to the ECD. He needs to run on the treadmill daily to keep him comfortable.
- Changing medication was discussed some more. Coming off a medicine that is working runs the risk of a relapse, and then the same medication doesn't work a second time. This happens for many different cancers. Most people that came off V did so because of side effects. But theoretically, V and D should have similar side effects.
- A Memorial Sloan Kettering trial link was shared, "Single-agent Cobimetinib for Adults With Histiocytic Disorders": <https://clinicaltrials.gov/ct2/show/NCT02649972>.
- A member came on and said that he has pain in his legs and fingers and that these are due to ECD. He has been on Kineret for 7 months.